

**DSTDP responses to STD Project Areas' questions and comments on proposed changes to the STD morbidity (or case) report reported to CDC via National Electronic Telecommunications System for Surveillance (NETSS)**

**Statistics and Data Management Branch, DSTDP  
December 14, 2007**

**I. CORE NETSS DATA**

**Event and Event Detection Information**

**Q. Date of Initial Exam and Specimen Collection Date seems redundant. Why are both needed?**

These date types may have the same value IF a specimen is obtained during the initial exam. DSTDP is recommending that date types be reported in a hierarchical fashion -- with preference being to report "date of specimen collection" as a date that is both epidemiologically relevant (i.e., more closely linked to patient health-care seeking vs. the STD program case investigation process) and less 'open' to interpretation. In situations where the dates are redundant (i.e., the same), then DSTDP would request that "date of specimen collection" be collected and reported.

**Q. How does specimen collection date differ from the currently used diagnosis date? Is this to try and account for estimated diagnosis date when the lab specimen data is missing?**

These date types may have the same value IF a specimen is obtained during the initial exam. DSTDP is recommending that date types be reported in a hierarchical fashion -- with preference being to report "date of specimen collection" as a date that is both epidemiologically relevant (i.e., more closely linked to patient health-care seeking vs. the STD program case investigation process) and less 'open' to interpretation.

**Q. In case of a paper-based report, the date of first report to local or state health department is when the report was mailed, received by the HD mailroom, or when actually entered into the surveillance system?**

The date of first report to local or state health department is equivalent to the date the information was physically received by the health department regardless of the method of receipt or the date on which the data were entered into an information system.

**Q. For an online system is the date of first report to local or state health department when the organization actually submitted the report**

**electronically, the date reviewed by the HD, or when the actual investigation was created?**

The date of first report to local or state health department is equivalent to the date the information was physically received by the health department regardless of the method of receipt or the date on which the data were entered into an information system.

**Q. The spreadsheet instructs us to report neurosyphilis cases of "unknown stage" with event code 10318. However, the CDC case definition for this code is "Syphilis, late, with clinical manifestations other than neurosyphilis." Neurosyphilis cases are by definition not late symptomatic syphilis cases, so we cannot use code 10318.**

DSTDP would prefer reporting be performed based on the March 2005 Dear Colleague Letter. "While neurosyphilis can occur at almost any stage of syphilis, in the past, it has been classified and coded as one of several mutually exclusive stages and as a distinct nationally notifiable condition in the National Notifiable Diseases Surveillance System

(<http://www.cdc.gov/epo/dphsi/casedef/syphiliscurrent.htm>).

- To improve and clarify reporting of neurosyphilis as a clinical manifestation of any stage of syphilis, the separate EVENT code (10317) for neurosyphilis was retired and should no longer be used.
- The variable "NEURO" (Neurological involvement in any stage of syphilis; Values: 1=Yes, confirmed, 2=Yes, probable, 3=No, 9=Unknown) was added to the NETSS record (column 95). This variable should only be reported for syphilis cases.
- If the patient has confirmed or probable neurosyphilis, select the appropriate stage of syphilis as the EVENT code and note the confirmed or probable neurological manifestations by using the NEURO data element."

DSTDP is currently discussing possible revisions to the 1996 STD Surveillance Case Definitions.

**Q. Why are records "4=Not a case" being included in the NETSS transfer for case status?**

Based upon input from the field, DSTDP will maintain the current variable "CASE STATUS" (column 53 in NETSS STD record) and its valid values. "Not a case" will not be a valid response for "CASE STATUS".

**Q. Is STD Rectype the same as "rectype"?**

No. DSTDP has reconsidered the STD Rectype variable and will NOT collect "STD Rectype" in the new STD morbidity report. "RECTYPE" (column 1 in NETSS STD record) will remain part of the STD morbidity report.

**Q. Is Facility type the same as "infosrce"?**

Yes. However, please review "Facility type/Infosrce" valid values in the new STD morbidity report. Some old values have been retired or discontinued and should not be re-used. Additionally, definitions are provided for all valid values. Project areas may need to provide re-orientation to their staff regarding the definition of this variable and its valid values.

**Q. Why not keep the labels the same?**

DSTDP has kept data variable labels the same when the meaning of the variable remains the same; when the meaning is different (even slightly), a new variable name will be used to minimize data interpretation errors resulting from our re-use of similar variable names or responses that have different meanings over time.

## **Race**

**Q. In the mapping sent it is hard to understand if 'RACE' are 8 variables or 1 variable. (i.e. white yes, no, or if you chose race=white it just means white=yes).**

Collection of multiple race information will require the use of multiple fields -- one per race group plus variables to record 'other race' or 'unknown race' information, or that the person 'refused to report race' information.

**Q. It is unclear if the NETSS file for all reportable STDs will continue to collect a combined race field as well as separate fields for each race category or will the separate race fields only be collected for syphilis cases?**

DSTDP will support the collection of multiple race information for each valid race group in accordance with the 1997 OMB Directive 15 guidance. We will NOT support the collection of a combined race variable in the revised STD morbidity report.

**Q. Generally speaking, people don't REFUSE to give race. Most often much of our STD work in the field starts with a laboratory test. Given that 70-75% of the testing is done in the PRIVATE sector, the race is not reported -- which is going to be UNKNOWN. This value seems out of place in public health work and seems equally out of place with each of the "Refused to Answer" options.**

"Refused to answer" as a valid response for some variables was an outcome of the DSTDP/DHAP data harmonization process. If this is not a valid response in a jurisdiction, then DSTDP would anticipate that no "Refused to answer" responses would be reported from that jurisdiction. It is a valid response for some jurisdictions.

## **II. EXTENDED or STD SPECIFIC DATA**

### **Event and Event Detection Information**

**Q. The new values under 'Method of Case Detection' will have an impact on historical data, reports and analysis. Many of the older codes have no**

**home. When attempting to convert the codes what can be done to prevent the loss of valuable data?**

DSTDP recognizes the potential confusion with the reuse of previous codes. In an effort to minimize the problem, two-digit codes that have not previously been used will be used. Previously, "Method of Case Detection" data were difficult to compare across jurisdictions because of variable classification protocols used by project areas. To try to improve understanding of the response categories and data quality, DSTDP is providing specific definitions for variable values.

**Q. What was the purpose for changing the 'Case Imported' values from numeric values to text values and changing the meanings - which again requires programs to evaluate the previous data for conversion?**

This variable is used in multiple national surveillance programs and the values reflect a harmonized and standardized data variable and values. Using such a data standard will result in discordance with previous program-specific data variables and values.

**Q. What is the purpose for the numerous date fields and what will be done with the information?**

DSTDP is requesting that date types be considered (and reported) in a hierarchical fashion -- both based on meaning of the date type and the jurisdiction's ability to collect and report the date type(s). The recommended date hierarchy for morbidity reporting is: 1) report date of specimen collection preferentially; If date of specimen collection is not available, report date of initial exam/diagnosis; and, if neither date of specimen collection or date of initial exam/diagnosis is available, report date of first report to local/state public health system. Project areas are encouraged to report as many types of dates as they have collected and entered into their local information system(s). For most federal analyses of surveillance data, DSTDP will use date of laboratory specimen collection as the main reference date for assignment of morbidity. We are promoting a date type hierarchy to emphasize our approach to temporal assignment of morbidity data and are accommodating several date types since all project areas do not uniformly collect and report any single date type. Specifying the type of date reported should improve our ability to interpret the case information in the context of the STD case investigation process.

## **Clinical Information**

**Q. Is lesion history for primary or both primary and secondary syphilis? If the client presents with one symptom but recalls seeing a chancre prior to exam how would this be coded?**

The new STD/HIV Interview Record (IR) captures both clinician-observed and patient-described signs and symptoms information regardless of diagnosed syphilis stage. For the purposes of reporting the data to CDC, DSTDP is only interested in clinician-observed lesion information for any stage of syphilis noted at the time of examination or at specimen collection.

**Q. What is the purpose for requesting a 30-character alphanumeric treatment field?**

DSTDP has reconsidered the value of reporting unstructured information on treatment to the federal level. While local project areas should have the ability to collect, analyze, and interpret information on the specific type of treatment received, until practical data standards exist for

representing and reporting types of medications and treatment regimens, DSTDP will not request information on treatment received as part of the morbidity report.

**Q. Is it the intent of CDC to capture the various dates the drug was administered?**

No. DSTDP is requesting that the "date treatment was initiated for the condition that is the subject of this case report" (regardless of the dosage or frequency of treatments that may be provided) be reported in the revised morbidity report.

**Q. Is it the intent of CDC to keep the STD\*MIS drug list up-to-date with the various changes in medications that are appropriate or recommended for a STD?**

No. As with prior releases of STD\*MIS, DSTDP will provide an initial 'starter set' of treatment regimen values for the treatment variable. STD\*MIS will continue to allow project areas to modify or supplement the initial set of treatment regimens provided. However, DSTDP will not be able to maintain up-to-date treatment regimen value sets. Also, please note that DSTDP is no longer requesting treatment information in the revised morbidity report.

**Q. Why is treatment documentation optional for Chlamydia and Gonorrhea, especially since some of the IPP Performance Measures are dependent upon treatment?**

Classifying a variable as "Optional" is intended to imply that if the data element is collected by a jurisdiction, DSTDP would like the jurisdiction to report the information as part of its morbidity reporting. "Optional" status is also intended to imply that the information remains relevant for state and local use, but DSTDP will not require complete reporting of that variable for all case reports.

## **Demographics**

**Q. How will Small set theory of releasing information be prevented with the receipt of census tract data at the national level?**

The reporting of census tract information is optional. If a project has the ability to collect and report this data, DSTDP would like to receive it. DSTDP will continue to follow the 1996 CSTE/CDC data release guidelines which would not allow DSTDP to release data by census tract (or any geographic unit smaller than county).

## **Laboratory Information**

**Q. Anatomic sites are poorly coded for data analysis. It's impossible to distinguish missing/skipped responses from true "No" responses. Could the answer choices be made consistent with other questions (yes/no/refused to answer/did not ask)?**

DSTDP understands that reporting the "Anatomic Site(s) of clinician-observed syphilis lesions" information by individual site and allowing multiple responses complicates data analysis. However, based on the way data would be derived from the IR (essentially only 'Yes' responses

would be coded and entered on the IR), the proposed method should translate directly from the IR to the morbidity report content.

**Q. We are getting resistance from the CDC HIV Surveillance side on integrating and/or capturing HIV information. We would require a letter of support from CDC HIV Surveillance Program Consultant stating that they concur with this request. Also need the letter to encourage the state HIV Surveillance Program to share this information with STD Programs.**

DSTDP is aware certain State/Local regulations or policies may restrict the availability of data. Programs are requested to report the information when available. However, information on STD-HIV co-morbidity is important for appropriate clinical case management and risk reduction counseling.

**Q. It would be helpful to differentiate between documented and self-report HIV status. Perhaps a PS=Positive self-report and PD=Positive documented could be used.**

This is a good ideal and would be very beneficial for analysis at the Local level. At the present time DSTDP is not concerned with capturing this degree of detail at the national level.

**Q. Some would question if Urine, Blood and Cerebrospinal fluid are not anatomic sites on the human body. Are these PHIN standards?**

DSTDP generated the value set for this variable to represent the appropriate specimen type or anatomic site from which the specimen was obtained. DSTDP recognizes that different concepts are included in the value set for this variable but considers that data analysts will be able to interpret the reported information at data entry and during analysis. For this variable, DSTDP chose to update the value set included in the revised IR. PHIN standards separate these concepts into two variables -- specimen type and anatomic site. We chose to simplify data collection and reporting in this instance.

**Q. Is the quantitative test result going to be free text? Also, you don't care what the test is just the value?**

DSTDP has reconsidered this issue and added the variable, "Nontreponemal syphilis test type", to the STD morbidity report. The quantitative value for the non-treponemal test is a maximum 4-digit numeric field. For example, if the non-treponemal test titre is 1:64, the reported value is "64" or if the non-treponemal test titre is 1:1024 the reported value is "1024"..

## **Risk Factor and Social History Information**

**Q. Currently, PARTNER field is completed for syphilis cases. There are also several fields asking information about sex of sex partners (new variable list). Does this mean the current PARTNER field will be deleted?**

Yes, the current PARTNER field will be deleted. However, in order to ensure that we do not lose data when retrospectively collected data are reported using the new report format. Project areas will be expected to convert the data in the existing partner field to the new format when creating the NETSS record for transmission. DSTDP will provide technical assistance as needed.

**Q. Having these options (D and R) implies that a high volume of R or D will prompt offers of "technical assistance" or reflect negatively on the program. Is this correct?**

It is not possible to interpret a blank response, thus the variable values -- R (refused to answer) and D (did not ask) -- provide an explanation as to why data may not be reported. Additionally, these response categories were standardized and harmonized by DSTDP and DHAP.

**Q. The validity and usefulness of 'Did Not Ask' was questioned as a response. Who is going to admit that they did not ask a required risk factor question for a syphilis patient?**

The definition of valid responses for some data variables resulted from a DSTDP/DHAP process to harmonize risk factor and social history questions and the "Did not ask" response was included as part of that process. It is likely that during analysis, the responses "Refused to answer" and "Did not ask" will be combined with missing responses to indicate a lack of reported information for the specific question. For some jurisdictions, "Did not ask" is a valid response.

**Q. Could the answer choices for injection or non-injection drugs in the past 12 months be made consistent with other risk questions (yes/no/refused to answer/did not ask)?**

At the present time the DSTDP/DHAP harmonization process has led to the "Select all which apply" question and response structure for this question.

**Q. Does CDC really want to capture open-ended 'Other drug(s) used' text from 65 project areas?**

No, DSTDP is no longer requesting that open-ended "Other drug(s) used" information be reported as part of the new STD morbidity report. However, project areas are encouraged to collect, analyze and interpret specific information on 'other' type(s) of drug(s) used since it may have direct relevance for planning and implementing STD outreach, prevention, and control activities.

**Q. Erectile dysfunction (ED) Drugs: Do you want to include herbal supplements along with the usual suspects of Viagra, Cialis, Levitra?**

No. CDC is requesting information on use of only those erectile dysfunction drugs that can be legally obtained through prescription. Over-the-Counter (OTC) herbal medicines or remedies to treat ED should NOT be considered 'eligible' ED drugs for the purposes of this question.

**Q. Why differentiate male or female with the risk factor question, "Had sex with a person who is known to her to be an MSM within the past 12 months"? This information could be deduced from the variables we send down in the NETSS file with a simple query.**

Upon re-review of the data variables, it is not evident that this information could be derived from other data variables. Therefore this variable (which resulted from the DSTDP/DHAP data harmonization process) provides unique information -- such as, relative magnitude of disease transmission between MSM and women.

**Q. Are you serious? The risk factor question, "Had sex with a person who is known to her to be an MSM within the past 12 months", is only for women and only required for syphilis.**

Upon re-review of the data variables, it is not evident that this information could be derived from other data variables. Therefore this variable (which resulted from the DSTDP/DHAP data harmonization process) provides unique information -- such as, relative magnitude of disease transmission between MSM and women.

### **III. OTHER**

**Q. Requiring these changes to be effective Jan. 1, 2008 is not realistic, especially since the final file format is still open for discussion and possible change. Is the date subject to change?**

DSTDP encourages all project areas to begin using the enhanced Interview Record (IR) or to collect these data elements in another format prior to January 1, 2008. DSTDP understands that reporting of the new STD morbidity report content may be delayed by the finalization of the morbidity record structure (including data variables, value sets, and formats) and the time needed for information systems to be modified.

**Q. Is there an implementation date that CDC expects all states to begin using the new IR?**

DSTDP considers that the new IR will benefit STD prevention programs by consistently collecting information on risk behaviors, places where partners were met, and previous STD/HIV test results. Through regular review of these standardized data, programs will be able to better understand who is becoming infected and why; they will also be able to monitor trends in behavioral risk factors. Therefore, DSTDP recommends, but does not require, the use of the new IR. DSTDP encourages project areas to begin using the enhanced IR by the end of December 2007. The STD morbidity report to CDC has been modified to include reporting of some new information. All Project Areas will be required to report these new morbidity report variables beginning January 1, 2008 regardless of whether or not they choose to use the new IR. (see previous comments regarding delayed implementation)

**Q. When will a document that lists ALL of the variables, in the correct order, field names and column numbers. A notation could be made as to whether this is a: New variable (with element legal values and descriptions) Revised variable (with element legal values and descriptions) Unchanged variable (with new element values and descriptions) Deleted variable (element is no longer used)**

The updated NETSS Implementation guide for STD morbidity reporting will designate all variables and their status. In the material that we distributed for review, SDMB tried to highlight changes in the record ONLY. SDMB assumed that jurisdictions were familiar with content of the current STD morbidity record (last updated in 2005).

**Q. Why are most of the new variables required for syphilis but optional for the other diseases?**

Based on the wide range in disease incidence by STD, DSTDP did not consider it realistic to expect complete reporting of all variables for CT & GC case reports as compared to syphilis. Since syphilis control programs remain focused on elimination, the additional information recommended as "required" for syphilis cases, especially P&S, is considered important to report to the national level to improve our understanding the dynamics of syphilis transmission in different communities. Additionally, much of the new information recommended to be reported would be elicited during the interview process, which in many jurisdictions is not conducted for CT & GC cases. Classifying a variable as "Optional" is intended to imply that if the data element is collected by a jurisdiction, DSTDP would like the jurisdiction to report the information. "Optional" status is also intended to imply that the information remains relevant for state & local use, but DSTDP will not require complete reporting of that variable for all case reports.

### **Non-STD\*MIS Sites**

#### **Q. Will non-STD\*MIS states have ample time to make the proposed changes and validate the changes?**

DSTDP encourages all project areas to begin using the enhanced IR or to collect these data elements using some other method prior to January 1, 2008. DSTDP understands that reporting of IR data elements may be delayed by the finalization of these elements (including data variables, value sets, and formats) and the time needed for information systems to be modified. DSTDP will work with sites who have identified impediments to the collection and reporting of the requested variables on case-by-case basis. All sites are encouraged to begin reporting STD morbidity information using the new report format as early as possible in CY 2008.

#### **Q. Is CDC providing any onetime funding grants to allow non-STD\*MIS users to make the changes? If not, is CDC open to allowing project areas to utilize carryover funding to make these changes?**

DSTDP will work with project areas who have identified impediments to the collection and reporting of the requested variables on case-by-case basis. All sites are encouraged to begin reporting STD morbidity information using the new report format as early as possible in CY 2008.

### **STD\*MIS Sites**

#### **Q. Before implementation of new IR does 5.0 need to be in place since the data required cannot be captured by MIS 4.x?**

No. DSTDP will provide an interim version of STD\*MIS – Version 4.1 -- to support the reporting of the revised STD morbidity record content (to be reported beginning 1 January 2008). STD\*MIS 5.0, but not 4.1, will support the collection of all variables on the revised IR in addition to all data variables in the modified STD morbidity case report.

#### **Q. It would be helpful if the morbidity record layout for both 4.1 and 5.0 will be provided.**

DSTDP is updating the NETSS Implementation Guide for STD Morbidity Reporting guidance to include the revised morbidity report specifications. The revised morbidity record layout will have

the same format/structure regardless of the information system(s) that is used to collect the data. Both STD\*MIS version 4.1 and 5.0 will extract and report the revised STD morbidity record.

**Q. Will new versions of STD\*MIS ensure treatment records added to cases are suitable for the diagnosis?**

STD\*MIS Version 4.1 will not provide a context-specific list of possible treatment regimens based on type of STD. At this time, STD\*MIS 5.0 does not support this functionality. But, STD\*MIS could be modified to support this function IF it were determined to add value greater than the DSTDP programming effort needed for development, testing, implementation, and maintenance.

**Q. Will the partner services Performance Measures (PM) report be properly modified to capture required data from STD MIS 5.0?**

Yes. DSTDP understands that modifying the information collected on the revised IR (and supported in STD\*MIS 5.0) may require changes in analysis routines -- including those supporting calculation of the Performance Measures. DSTDP staff are currently reviewing STD\*MIS Version 5.0 to determine if programs calculating PMs need to be modified based on changes to either the morbidity record format or Version 5.0.